

Secondary. Not Second Rate

Incurable should not mean unsupported

The importance of ongoing, specialised support

Breast cancer patients represent the largest cancer patient group in the UK, with approximately **691,000** people. This is predicted to rise to **840,000** in 2020³. It is estimated that about 30% of patients with primary breast cancer will develop secondary breast cancer⁴.

Breast Cancer Care believes that there is a clear need for specialised support for people living with secondary breast cancer – to help manage the complex physical and emotional effects of the disease.

However, there is no specific commitment to provide a comprehensive package of support tailored for people living with **incurable cancers** in UK cancer strategies. This is despite the fact that we know people living with a diagnosis of secondary breast cancer often have complex emotional and physical needs.

The Cancer Strategy for England (2015-2020)⁵ includes an ambition that every person with cancer has access to elements of a Recovery Package by 2020. However, these measures are focused on supporting people after they have completed hospital-based treatment for primary cancer. Similarly, the Scottish Cancer Strategy, Beating Cancer: Ambition and Action⁶, focuses on supporting people to live with and beyond cancer through the Transforming Care after Treatment (TCAT) programme. The Cancer Delivery Plan for Wales 2016-2020⁷ recognises the need to 'better meet the needs of people who have finished their treatment' and supports the rollout of access to elements of the Recovery Package across Wales.

There is no cancer strategy in place for Northern Ireland.

'My whole life and the lives of those around me fell apart and changed forever. Following my diagnosis, in the space of a 20-minute consultation, I felt I lost my identity and my future with those I love.'
Jo, diagnosed aged 40

What patients are telling us

Patients frequently tell us they feel as though support is not always available. As part of our **Secondary. Not Second Rate** campaign, we surveyed people living with secondary breast cancer. We found that the support many people experience is inferior to the support received by people with primary breast cancer.

The majority of people told us they were given information at diagnosis (55%) but the evidence shows **that support tends to wane as treatment progresses**: 41% of people were given information during treatment while only 16% were given information as their secondary breast cancer changed and only 20% were given information as their treatment changed. Almost one in five (16%) were not given any information at any stage⁸.

This simply isn't good enough: incurable shouldn't mean unsupported. That's why we want to see everyone living with incurable breast cancer receive the care and support they need, when they need, it through a Secondary Support Package.

A Secondary Support Package for everyone with secondary breast cancer

To ensure no-one diagnosed with secondary breast cancer feels unsupported, Breast Cancer Care recommends there should be a **Secondary Support Package** available for people with secondary cancers, including secondary breast cancer. This Secondary Support Package would provide similar elements to the Recovery Package, adapted to meet the unique needs of people living with a secondary breast cancer diagnosis, such as:

- access to a clinical nurse specialist (CNS) with the skills, knowledge and experience of secondary breast cancer, and specific time and resource to support them
- a formal assessment of physical, emotional and information needs at the point of diagnosis and as treatment changes
- provision of timely and relevant information about specialist support services
- a treatment summary after each significant phase of treatment
- a tailored health and wellbeing event

Current provision of specialised support for secondary breast cancer patients in England, Scotland, Wales and Northern Ireland

To help us build a picture of current availability of specialised, ongoing support for secondary breast cancer patients across the UK, Breast Cancer Care sent Freedom of Information (FOI) requests to NHS hospital trusts and health boards.

We asked hospital organisations whether:

- patients have access to a dedicated secondary breast cancer CNS
- patients receive a holistic needs assessment (HNA) at the point of diagnosis and as their disease changes
- patients receive a treatment summary following each significant phase of treatment
- patients have access to a relevant health and wellbeing event

We received a response from 84% of these organisations.

Key findings

Access to a secondary breast cancer CNS

We know that access to a CNS is the biggest factor in improving patient experience. Almost three quarters (72%) of NHS Trusts and Health Boards across England, Scotland and Wales do not provide a dedicated nurse for people living with incurable breast cancer. This is compared to 95% of people with primary breast cancer in England that have access to a CNS, according to the National Cancer Patient Experience Survey⁹.

In 2016, we asked hospital organisations in England, Scotland and Wales whether patients had access to a dedicated secondary breast cancer nurse. Only 21% of organisations had one or more nurse specialists dedicated to secondary breast cancer¹⁰.

We were able to analyse our latest findings to assess progress over the past two years. We were disappointed to see little progress. Across England, Scotland and Wales, only 28% of hospital organisations have one or more CNS dedicated to caring for secondary breast

cancer patients, representing an increase of only 7% since 2016. This is despite access to a CNS being highlighted across all UK cancer strategies.

Some hospitals have CNSs working in a ‘combined’ role. A combined CNS role is defined as a CNS with responsibility for both primary and secondary breast cancer patients as part of their agreed job role. We recognise that there are certain instances where this will be sufficient – for example in smaller hospitals with a smaller patient group. However, this role also poses challenges. For example, it is very difficult to assess how much time a combined nurse specialist has to spend with primary breast cancer patients compared to secondary breast cancer patients, and therefore difficult to confirm whether secondary breast cancer patients are fully supported.

In 2015/16, cancer strategies in England, Scotland and Wales were published, and all included a commitment for patients to have access to a specialist nurse. Three years on, the fact that seemingly very little progress has been made to turn these commitments into reality means that patients continue to be left unsupported to manage the impact of this disease.

Breast Cancer Care wants everyone with secondary breast cancer to have access to a CNS with the appropriate skills, knowledge and experience of secondary breast cancer, and specific time and resource to support these patients. This would ensure they are fully supported from diagnosis, through treatment and end-of-life care.

Table 1: percentage of organisations that have one or more dedicated CNS

England	Scotland	Wales	UK average
34%	25%	20%	28%

Planning services to support secondary breast cancer patients

To gain an understanding of whether patients were being effectively supported by a secondary breast CNS, we asked hospitals to tell us how many patients with secondary breast cancer are currently under their care (see Table 2). We were disappointed that two-fifths (40%) of organisations were unable to provide us with this information.

Further analysis shows that there were two broad reasons for this. Either they were simply not recording the number of people diagnosed with secondary breast cancer or they applied an exemption on the basis of time and cost. One trust told us it would take in excess of 1,000 hours to provide the information.

If hospitals do not know how many people with secondary breast cancer are under their care, they will be unable to plan services effectively to ensure patients are fully supported from diagnosis, through treatment and end-of-life care.

We are pleased that there has been some progress on this issue in England as a result of our campaigning over the past two years. We have worked with Public Health England to improve data collection guidance for hospital staff. We also welcomed the update to the Cancer Outcomes and Services Dataset (COSD – the dataset hospitals in England submit data on the number of people diagnosed with secondary breast cancer) in April 2018. This update means that hospital trusts in England can differentiate between a recurrence of breast cancer and secondary breast cancer, which will result in far more accurate data being recorded.

However, despite these improvements, our latest research clearly shows that there is more work to be done to ensure that every hospital in the UK is recording the number of people diagnosed with secondary breast cancer.

Table 2: percentage of organisations unable to tell us how many patients with secondary breast cancer were currently under their care

England	Scotland	Wales	Northern Ireland	UK average
38%	42%	80%	50%	40%

Holistic needs assessment (HNA)

As a framework for a conversation between a patient and healthcare professionals, the HNA allows the patient to highlight their individual needs in relation to secondary breast cancer and provides the healthcare professional with an opportunity to signpost that patient to appropriate support services. An HNA is crucial to ensuring patients feel fully supported from the point of diagnosis.

The importance of the HNA is highlighted in Breast Cancer Care's **Standards of Care on Secondary Breast Cancer**¹¹ report, which highlights the importance of 'timely, high-quality information and support at diagnosis and onwards from a CNS who is skilled and knowledgeable in the treatment and care of people with secondary breast cancer'. This complements the National Institute for Health and Care Excellence guideline for Advanced

Breast Cancer¹², which currently states, in line with policy initiatives across Scotland and Wales, ‘that an assessment and discussion of patient need for physical, psychological, social, spiritual and financial support should be undertaken at key points (such as diagnosis; at commencement, during, and at the end of treatment; at relapse; and when death is approaching)’.

Through a Secondary Support Package, people living with secondary breast cancer would benefit from an HNA throughout their treatment and towards end-of-life, not just at diagnosis.

‘The support I received following my diagnosis was non-existent. There were no specialist or secondary breast cancer nurses.’

Jo, diagnosed aged 40

Table 3: percentage of organisations that provide an HNA at the point of diagnosis and as treatment changes

England	Scotland	Wales	Northern Ireland	UK average
31%	25%	33%	25%	30%

Treatment summaries

The Recovery Package, as outlined in the Cancer Strategy for England, recommends that primary breast cancer patients should receive a cancer care review and treatment summary after finishing hospital-based treatment.

For secondary breast cancer patients, Breast Cancer Care recommends that they should receive a treatment summary at the end of each significant phase of treatment. The treatment summary would include information on how they have responded to the treatment, document any side effects and include information about the next steps, such as referral to

support services. Whereas the treatment summary is used as a final summary document for patients with primary breast cancer, for secondary cancers it should be used as an ongoing resource, continually updated by patients and healthcare professionals.

The treatment summary would also be an important tool to aid communication between different healthcare professionals across primary, secondary and palliative care. For example, it would provide a GP with access to information about a patient's past treatments, side effects and symptoms, thereby connecting primary and secondary care.

However, as Table 4 shows, very few hospital organisations are currently providing patients with a treatment summary. This could hinder communication and coordination between primary, secondary and palliative care teams, and risk patients feeling like their care is not joined up.

Through a Secondary Support Package, every secondary breast cancer patient would receive a treatment summary at the end of each phase of treatment.

Table 4: percentage of hospital organisations that provide all patients with a treatment summary at the end of each phase of treatment

England	Scotland	Wales	Northern Ireland	UK average
20%	17%	0%	0%	18%

Tailored health and wellbeing support

The importance of providing tailored health and wellbeing information and support after a diagnosis of and treatment for breast cancer is well evidenced. It can help people feel more supported and informed about their treatment and care options, reduce isolation and help to maintain good quality of life.

Breast Cancer Care runs such events for people with secondary breast cancer through our Living with Secondary Breast Cancer service. These events run every month in 36 locations across the UK. The sessions provide information on topics such as pain management, treatments and side effects. They also offer attendees a space to talk openly to other people in a similar situation. Facilitated by a counsellor and with regular professional guests such as CNSs, benefits advisers and others, the sessions provide information and support in a relaxed environment. A recent evaluation of the service demonstrated the clear impact of the

service on the quality of life of participants: 78% of women said the service had helped them feel better able to manage living with secondary breast cancer.

As part of a Secondary Support Package, patients would be referred to a health and wellbeing event, specifically tailored for secondary cancers. This event would focus on living as well as possible for as long as possible.

However, **only 47%** of hospitals offer secondary breast cancer patients access to tailored health and wellbeing events. This means that patients are missing out on this vital support, which could exacerbate feelings of isolation and a lack of support.

Through a Secondary Support Package, everyone would have access to a tailored health and wellbeing event.

Table 5: percentage of hospital organisations that provide access to a tailored health and wellbeing event for secondary breast cancer

England	Scotland	Wales	Northern Ireland	UK average
47%	55%	40%	25%	47%

What this means for patients

Our findings show that people with secondary breast cancer are unable to access the vital specialist support they need, when they need it.

To address these significant gaps in support, Breast Cancer Care recommends there should be a **Secondary Support Package** available for people living with secondary breast cancer. The Secondary Support Package would meet the unique needs of people living with secondary breast cancer. It would ensure access to a CNS, an HNA and referral to tailored health and wellbeing support.

These gaps need to be urgently addressed – because incurable should not mean unsupported.

Recommendations

Breast Cancer Care is calling for everyone with secondary breast cancer to have access to a Secondary Support Package when diagnosed, through treatment and during end-of-life care.

- **UK Governments must introduce a Secondary Support Package for everyone with secondary breast cancer at the point of diagnosis. This package should include the support listed below.**
 - **Access to, and support from, a secondary breast cancer clinical nurse specialist (CNS). The CNS would act as a point of contact, be an advocate, help coordinate treatment and care planning, and signpost or refer to relevant support services.**
 - **A Holistic Needs Assessment conducted at diagnosis and as treatment changes. This should include a comprehensive assessment of emotional, physical and information needs, including a consideration of palliative care needs.**
 - **A treatment summary, updated by clinical staff and the patient, at the end of each significant phase of treatment, and as appropriate. The treatment summary should meet the specific needs of people with secondary breast cancer and aid communication between secondary, primary and palliative care.**
 - **Referral to a tailored health and wellbeing service. This service should include psychological support and opportunities to meet other people with secondary breast cancer.**
- **UK Governments must provide funding to recruit and train CNSs for secondary breast cancer to address the current gap.**
 - **HM Treasury must make funding available in the upcoming spending review. This funding must include an increase in Health Education England's budget.**
 - **The Scottish and Welsh Governments must increase the funding available to NHS bodies to recruit and train secondary breast cancer clinical nurse specialists.**
- **Cancer Alliances and Cancer Networks must roll out the Secondary Support Package across the UK.**

- **Hospital Trusts and Health Boards across the UK must implement the Secondary Support Package, supported by guidance from cancer alliances and cancer networks.**

Further information

To find out more about the **Secondary. Not Second Rate** campaign, please contact campaigns@breastcancercare.org.uk or call Gunes Kalkan, Head of Evidence, Policy and Campaigns on 0207 960 3447. You can also visit Breast Cancer Care's website

breastcancercare.org.uk/secondary

¹ Formal data collection is inconsistent. Statistics are an estimate taken from: Using routinely collected data to stratify prostate cancer patients into phases of care in the United Kingdom: implications for resource allocation and the cancer survivorship programme, Yip, K.

McConnell, H. Alonzi, R. and Maher, J. British Journal of Cancer, 2015

² Cancer Research UK mortality numbers from 2014-2016, only invasive breast cancer (doesn't include DCIS)

³ Maddams J et al (2012) Projections of cancer prevalence. British Journal of Cancer, 107 (7) 1195-1202

⁴ Early Breast Cancer Trialists' Collaborative Group (2005) Effects of chemotherapy and hormonal therapy for early breast cancer on recurrence and 15-year survival: an overview of randomised trials. Lancet, 365: 1687–717

⁵ Independent Cancer Taskforce (2015), Achieving World Class Outcomes: A Cancer Strategy for England 2015-2020

⁶ Scottish Government (2016), Beating Cancer: Ambition and Action, The Scottish Government

⁷ Wales Cancer Network (2016), Cancer Delivery Plan for Wales 2016-2020

⁸ Breast Cancer Care figures from 2016-2016 **Secondary. Not Second Rate** campaign, available at breastcancercare.org.uk/secondary

⁹ National Cancer Patient Experience Survey (2017) available at: ncpes.co.uk/reports/2017-reports/national-reports-1

¹⁰ Breast Cancer Care (2016) Secondary. Not Secondary Rate: Nursing Support, available at breastcancercare.org.uk/secondary

¹¹ Breast Cancer Care (2016) Standards of Care for Secondary Breast Cancer, available at breastcancercare.org.uk/information-support/secondary-metastatic-breast-cancer/standards-care-secondary-breast-cancer-patients

¹² National Institute for Health and Care Excellence (NICE) (2009 updated 2014), Advanced breast cancer: diagnosis and treatment (CG81), available at nice.org.uk/guidance/cg81